# GOVERNMENT OF INDIA
# HEALTH AND FAMILY WELFARE
# LOK SABHA

STARRED QUESTION NO:250
ANSWERED ON:14.03.2001
RISING OF THALASSAEMIC DISEASE
BASUDEB ACHARIA;RAMESH CHAND TOMAR

**Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:**

(a) whether the number of persons suffering from thalassaemic disease are increasing day-by-day in the country, as reported in the Times of India dated January 11, 2001;

(b) if so, the facts thereof;

(c) whether drugs for Thalassaemics are costly and are out of reach of common man;

(d) if so, whether the Union Government have provided any assistance to the State Governments to deal with the situation; and

(e) if so, the details thereof?

## Answer

MINISTER OF HEALTH AND FAMILY WELFARE (DR. C.P. THAKUR)

(a) to (e): A statement is laid on the Table of the Lok Sabha.

STATEMENT REFERRED TO IN REPLY TO LOK SABHA STARRED QUESTION NO. 250 FOR 14.3.2001

RISING OF THALASSAEM1C DISEASE

(i) There is no centralised or state-wise registry regarding prevalence of thalassaemic in the country. It has been estimated that upto ten thousand children with thalassaemia are born every year in the country.

(ii) (a) The cost of therapy varies between Rs.80,000 to Rs.1,00,000/- per year per child. Many thalassaemia societies are also offering chelator drug either free of cost or at reduced cost.

(ii) (b) The curative treatment for thalassaemia major is through bone marrow transplantation. This facility is available at Christan Medical College, Vellore at a cost of Rs.5 to 10 lakhs approximately per case.

(iii) A National Illness Assistance Fund is set up under the Department of Health, Ministry of Health & Family Welfare. The proposal for setting up of the fund was approved by the Committee on Non-Plan Expenditure in its meeting held on 17thOctober, 1996. Accordingly the National Illness Assistance Fund has been set up vide Resolution No.F-7-2/96-Fin.II dated 13/1/97 as published in the Gazette of India (Extraordinary) and has been registered under the Society Registration Act, 1860, as an autonomous Society. This was set up with an initial contribution of Rs.5 crores from Ministry of Health & Family Welfare. The Fund could also be subscribed by Individuals in India or abroad with the approval of FCRA, Corporate bodies in private or public sector, philanthropic organisations and all contributions made to this Fund are exempted from payment of Income-Tax under section 80-G of Income Tax Act, 1961.

(iv) All State Governments/U.T Administrations have been advised vide Ministry of Health & F.W. letter dated 11.11.96 to set up an Illness Assistance Fund in their respective States/U.Ts. The Grants-in-aid to States/U.Ts is given to the extent of 50% of the contributions made by State Govts./U.Ts to the State Fund/Society subject to a maximum of Rs.5 crores to states with larger number and percentage of population below poverty line viz. Andhra Pradesh, Bihar, Madhya Pradesh, Karnataka, Maharashtra, Orissa, Rajasthan, Tamil Nadu, Uttar Pradesh and West Bengal and Rs.2 crores to other States/U.Ts. The State/U.T level Funds could also receive contributions/donations from donors, as mentioned for NIAF. The Illness Assistance Fund at the State/U.T level would release financial assistance to patients living in their respective States/U.Ts upto Rs.1.5 lakhs in an individual case and forward all such cases to NIAF, where the quantum of financial assistance is likely to exceed Rs.1.5 lakhs.

(v) The Fund will provide financial assistance to patients, living below poverty line, who are suffering from major life threatening diseases, to receive medical treatment at any of the superspeciality Hospitals/Institute or other Government Hospitals. The financial assistance to such patients would be released in the form of `one-time-grant`, which will be released to the Medical Superintendent of the Hospital in which the treatment has been/is being received. In a bid to speed up the assistance to the needy patients, the Scheme has been modified (In January, 1998) and an advance of Rs.10 lakhs has been kept with the Medical Superintendent of AIIMS, New Delhi, Dr. RML Hospital, Safdarjung Hospital, LHMC & Smt. S.K. Hospital, New Delhi and PGIMER, Chandigarh, JIPME

Pondicherry, to enable sanction of an amount of Rs.50,000/-(as substituted from Rs. 25,000/- w.e.f. 11.1.2001) in each deserving case reporting for treatment in the respective Hospital/Institute. The advance amount would be replenished as and when the report of its utilisation are received from the Hospital/Institute. N1MHANS, Bangalore and CNCI, Calcutta have also been included subsequently in this scheme (Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow and Gandhi Memorial and Associated Hospitals (KGMC), Lucknow have also been given an advance of Rs.15/- lakhs each recently).

(vi) The State Governments/U.Ts should take advantage of this scheme so that maximum of poor patients can avail this treatment.